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IN THE

SUPREME COURT OF THE UNITED STATES

OCTOBER TERM, 1995

MARY MARTIN, Guardian of Michael Martin,

Petitioner,

v.

PATRICIA MAJOR and LEETA MARTIN,

Respondents.

AMICI CURIAE BRIEF IN SUPPORT OF RESPONDENT'S RESPONSE TO PETITION FOR WRIT OF CERTIORARI

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The Arc of Michigan
The Autism Society of Michigan
United Cerebral Palsy
The Association for
Community Advocacy
The Disability Network
American Disabled for Assistant
Programs Today
The Disability Rights Bar Association
The American Association of
Mental Retardation
National Legal Center for the Medically
Dependent & Disabled, Inc.

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STATEMENT OF INTEREST OF AMICI CURIAE

This Brief is submitted on behalf of ten organizations devoted to the protection of the rights of persons with disabilities. Amici represent persons with various disabilities -- including mental retardation, autism, and traumatic brain injury -- and offer this Brief on behalf of their constituencies, whose interests will be profoundly affected by this Court's decision.

Michigan Protection and Advocacy Service (MPAS) is the Michigan agency charged with implementing the federal protection and advocacy (P&A) statutes enacted to protect the legal rights of people with disabilities.[1] The P&A statutes express Congress' belief that disability is part of the human condition, that people with disabilities have value, and that their voices -- regardless of legal competence or the severity of impairment -- must be heard. MPAS, in conjunction with nine other advocacy organizations, asks this Court to let amici be their voice here. Not only will amici's constituents be affected by this Court's decision, but amici have seen how decisions to terminate life support are sometimes made in the real world.

MPAS' mission is to advance the dignity, equality, self-determination, and expressed choices of individuals. To that end, and in harmony with Congress' core policy, MPAS has been significantly involved in the legal, legislative, administrative, institutional, and civic processes impacting on people with disabilities and their rights.

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[1] The statutes are the Developmental Disabilities Assistance and Bill of Rights Act of 1975, 42 U.S.C. 6000 *et. seq.*, the Protection and Advocacy for Mentally Ill Individuals Act of 1986, 42 U.S.C. 10801 *et. seq.*, and the Protection and Advocacy for Individual Rights Act of 1992, 29 U.S.C. 794e(a). Pursuant to M.C.L. 330.1931, MPAS is the designated agency in Michigan to represent the rights of the persons protected by these statutes, and Michael Martin is within the class of persons protected. 29 U.S.C. 794e(a).

MPAS has substantial experience in cases addressing fundamental rights, including representation of persons with disabilities in involuntary commitments, medical treatment decisions, and involuntary sterilization. The decades of experience of MPAS in protecting the rights of persons with disabilities renders MPAS uniquely qualified to assist this Court in its consideration of a petition which affects Michael Martin and the thousands of people who will live or die by the Court's decision in the years to come.

MPAS is joined in this Brief by nine other organizations committed to protecting the rights of persons with various handicapping conditions.

The Arc of Michigan (formerly the Association for Retarded Citizens or ARC) is a private, non-profit agency with a long history of advocating for the rights of Michigan's citizens who have mental retardation. The Arc, on a daily basis, assists persons with mental retardation to secure public services such as special education, vocational rehabilitation, and mental health services. The Arc's activities also include advocacy in guardianship and other issues affecting personal rights. It is the experience of the Arc of Michigan that all citizens, regardless of handicap, can live quality, productive lives in their communities.

The Autism Society of Michigan is a United Way, non-profit advocacy organization that represents Michigan citizens with autism and their families. Autism is a developmental disability which manifests itself by varying degrees of impairment in communication skills, cognitive functioning, and social interaction. The Autism Society advocates that all citizens with autism be fully included as valued members of our society.

United Cerebral Palsy (UCP) of Michigan is a membership agency which safeguards the rights and interests of persons with cerebral palsy. UCP is engaged in a wide variety of services, advocacy, and educational efforts on behalf of persons with cerebral palsy. Cerebral palsy is an impairment of brain function which affects motor control and coordination.

The Association for Community Advocacy (ACA) is a human service organization dedicated to promoting the general welfare of persons with developmental disabilities. ACA advocates for the rights of those it serves, promotes maximum opportunity for their participation in the community, and assures the provision of needed services.

The Disability Network is a Michigan agency that supports people with disabilities through education, consultation, and direct advocacy efforts in the areas of housing, transportation, attendant care, and many other services. The Network is committed to promoting the rights and opportunities of all people with disabilities.

American Disabled for Assistant Programs Today (ADAPT) is a Michigan non-profit coalition of individuals and organizations who work with other national ADAPT programs to provide community-based personal assistance services. ADAPT is working for change in any area where the rights of persons with disabilities are in jeopardy.

The Disability Rights Bar Association (DRBA) is a special purpose organization recognized by the State Bar of Michigan. DRBA's purpose is to encourage the implementation of disability rights law for all Michigan citizens with disabilities. Pursuant to this purpose, the DRBA provides resources and assistance to the private

bar to assist in the representation of persons with disabilities to secure their legal rights.

The American Association of Mental Retardation (AAMR) is the Michigan Chapter of a national organization. AAMR promotes educational and advocacy efforts on behalf of citizens with mental retardation. The Michigan chapter particularly promotes inclusion and maximum community opportunities for all persons with disabilities.

The National Legal Center for the Medically Dependent & Disabled, Inc. provides legal advocacy to persons with disabilities by defending their medical treatment rights against denials based on rationing, "quality of life" surrogate decision making, and discriminatory animus. The National Legal Center has participated in numerous court cases regarding life-sustaining treatment decision making, including the Supreme Court case of *Cruzan v. Director, Missouri Department of Health.*

Amici, as a result of their history of representing the interests of persons with disabilities and their first-hand knowledge of the devaluation and vulnerability of such persons, have serious concerns that a review of the case will upset the important balance of competing interests the Michigan Supreme Court has carefully crafted. Amici's constituencies include thousands of Michigan citizens who were born with severe cognitive impairments and who have never been legally competent or capable of exercising "informed consent." Such persons, like Michael Martin, nevertheless have "capacities" and the ability to express "personal needs and preferences." 42 USC 6000(a)(3). The Michigan Supreme Court appropriately created safeguards to protect the liberty and life interests of individuals with disabilities. Without these vital safeguards, the life support of these citizens can be terminated -- even if they are not terminally ill, in a

persistent vegetative state, or in pain -- regardless of their expressed choices.

Amici are also alarmed about the result that might occur if the Michigan safeguards are relaxed: surrogate decision-makers, with their own distinct and potentially conflicting interests, will be empowered to make a quality of life judgment that will result in the death of another human being.

SUMMARY OF ARGUMENT

Michigan, pursuant to this Court's deference to the "laboratory of the States," has further defined the qualitative meaning of the "clear and convincing evidence" standard which this Court has previously found to be a permissible regulation on decisions to terminate life support for an incompetent person. In crafting appropriate safeguards, Michigan has carefully considered the unique circumstances of the present case -- including the fact that Michael Martin is not terminally ill, in a persistent vegetative state, or in pain -- and the available sources of Michigan law and policy.

Further, the evidence on record indicates that Michael Martin is expressing the current desire to live, and this desire should be controlling in light of Mr. Martin's fundamental liberty interest and the complementary interests of Michigan, including those interests expressed in its recent Patient Advocacy Act. Michigan's Act is part of a nationwide effort of the States to fill in the details regarding the standards and procedures to be employed in termination of life support cases. These standards uniformly reject withdrawal of life support in the circumstances presented here, demonstrating that Michigan's regulation is consistent with the concept of ordered liberty.

Thus, review of Michigan's decision is not called for. Michigan, advancing interests of the highest magnitude -- to preserve life, protect individual liberty, and protect incompetent persons from conflicts of interests -- has properly rejected uncorroborated testimony of an interested party regarding previous statements about medical treatment and surrogate designation. Review is also unnecessary given the extensive and careful State regulation across the nation.

ARGUMENT

As the Developmental Disabilities Assistance and Bill of Rights Act states, disability is a "part of the human experience."[2] Accordingly, the presence of a disability does not mean that an individual is deprived of the right to "enjoy self determination" and to "make choices."[3] These expressions of public policy are consistent with constitutional principles, including the substantive due process liberty interest of an individual to make decisions about medical care and treatment. In the view of amici, the present petition for certiorari is not so much about advance directives or about the designation of a surrogate for medical decision-making as it is about the current choices of a living individual, Michael Martin, to "exert control and choice" over his own life, despite his disability.[4]

In its decision in *Cruzan*,[5] this Court upheld a State practice of requiring clear and convincing evidence of an advance directive to terminate life support for an individual in a persistent vegetative state, noting:

> Today we decide only that one State's practice does not violate the Constitution; the more challenging task of crafting appropriate procedures for safeguarding incompetents' liberty interests is entrusted to the "laboratory" of the States.[6]

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[2] 42 U.S.C. 6000(a)(2).

[3] *Id.*

[4] 2 U.S.C. 6001(13).

[5] *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1990).

In the present case, the Michigan Supreme Court, pursuant to the challenge left open in *Cruzan* and cognizant of this Court's admonitions regarding the quality of evidence one would expect to support such a critical decision, has crafted a more detailed standard of what "clear and convincing evidence" must look like. In so doing, the Michigan Supreme Court, as *Cruzan* envisioned, had available to it "a number of sources ... which are not available to us,"[7] including the State's Patient Advocacy Act.[8] This Act clearly articulates the policy of Michigan regarding the safeguards required to protect the State's complementary interests in the preservation of life, the assurance that persons with disabilities retain their liberty interest in exerting control over their lives, and the protection of incompetent persons from over-reaching:

> A current desire by a patient, irrespective of a previous expressed or evidenced desire, to have provided, and not withheld or withdrawn, a specific life extending care, custody, or medical treatment shall be binding on the patient advocate, if known by the patient advocate, regardless of the then ability or inability of the patient

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[6] *Id.* at 292 (O'Connor, J., concurring).

[7] *Id.* at 277.

[8] Although the PAA was enacted subsequent to Mr. Martin's disability and therefore does not govern the case, it nevertheless provides persuasive guidance on the public policy of the State. More importantly for purposes of the request for certiorari, the recent enactment of such statutes in almost every State militates against granting review, as the laboratory of the State Legislatures, in conjunction with their court systems, has effectively filled any voids left in the wake of this Court's decision in *Cruzan*.

to participate in care, custody, or medical treatment decisions or the competency of the patient.[9]

Presumably, the discernment of the current wishes of the patient himself can be made in a way similar to determining the patient's current wish to revoke his designation of a surrogate: "at any time and in any manner by which he or she is able to communicate an intent."[10] In this regard, amici believe that the evidence on record indicating that Mr. Martin, through a series of hand squeezes which were checked for accuracy by an expert, has expressed the *current* intention to live is determinative under both the policy of Michigan's Patient Advocacy Act and under substantive due process, since a person does not lose his fundamental liberty interest when declared legally incompetent.

Neither such statutory safeguards, nor the Michigan Supreme Court's elaboration on the quality of evidence needed to reach the high level of "clear and convincing," constitutes an undue restriction on the individual's interest. Rather, as suggested above, the present case does not concern a conflict between the liberty interests of the individual and the interests of the State. Michigan's compelling interest in the preservation of life is complemented by Mr. Martin's current expressions of the desire to live. Further, given the Michigan Supreme Court's implicit skepticism about the uncorroborated testimony of an interested party, Michigan's strong *parens patriae* interest in protecting incompetent persons is added to this

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[9] M.C.L. 700.496(13) (emphasis added). Significantly, the Michigan Act recognizes that even persons who are legally incompetent may still be able "to participate in ... medical treatment decision.".

[10] M.C.L. 700.496(11)(d).

constellation of interests supporting Michigan's decision in the present case. [11]

As the Michigan Supreme Court duly noted, Michael Martin's situation is distinct from other "right to die" cases because he is not in a persistent vegetative state, terminally ill, or in pain. A review of the cases where withdrawal of life-sustaining treatment has been requested for a person who is legally incompetent reveals that no such requests were granted unless a persistent vegetative state, terminal illness, or a writing of sufficient solemnity was present.[12] Further, upon considering every living will statute in the nation, it can also be said that no State authorizes the withdrawal of life-sustaining treatment for an individual in Mr. Martin's condition absent a writing.[13] Michigan's safeguards are thus consistent with the concept of ordered liberty and with the procedures crafted by the States and do not merit review by this Court.

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[11] Based on their experiences, amici are especially concerned about transmuting the inquiry from the patient's previous wishes to the patient's purported designation of a surrogate. The amici's constituents are frequently vulnerable to conflicting financial and emotional interests, including the desire of family members to stop the perceived "suffering" of a loved one. Given such societal and familial pressures, a purported designation of a surrogate should require *additional* safeguards, not deference to a self-proclaimed surrogate.

[12] Meisel, *The Right to Die*, 122 (Cum. Supp. 1994).

[13] As these cases and statutes suggest, the State's interests in the preservation of life and the protection of incompetent persons increases in circumstances where, for example, the individual is not terminally ill or where the evidence of purported previous expressions of intent is inherently unreliable.

CONCLUSION

Accordingly, Amici urge this Court to deny the Petition for Certiorari.

Respectfully submitted,

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APPENDIX

M.C.L.A. 700.496

WEST'S MICHIGAN COMPILED LAWS ANNOTATED
CHAPTER 700. REVISED PROBATE CODE
ARTICLE 4. GUARDIANSHIP AND PROTECTIVE PROCEEDINGS
Current through the End of 1993 Regular Session

700.496. Patient designation of advocate for health care decisions; form, contents, and execution of designation; authority and limitations of patient advocate

Sec. 496. (1) A person 18 years of age or older who is of sound mind at the time a designation is made may designate in writing a person who is 18 years of age or older to exercise powers concerning care, custody, and medical treatment decisions for the person who made the designation. For purposes of this section, a person who is named in a designation to exercise powers concerning care, custody, and medical treatment decisions shall be known as a patient advocate and a person who makes a designation shall be known as a patient.

(2) A designation shall be in writing, signed, witnessed pursuant to subsection (3), dated, executed voluntarily, and before its implementation shall be made part of the patient's medical record with the patient's attending physician and, if applicable, with the facility where the patient is located. The designation shall include a statement that the authority conferred under this section shall be exercisable only when the patient is unable to participate in medical treatment decisions.

(3) A designation shall be executed in the presence of and signed by 2 witnesses. The witnesses shall not be the patient's spouse, parent,

child, grandchild, sibling, presumptive heir, known devisee at the time of the witnessing, physician, patient advocate, an employee of a life or health insurance provider for the patient, an employee of a health facility that is treating the patient, or an employee of a home for the aged as defined in section 20106 of the public health code, Act No. 368 of the Public Acts of 1978, being section 333.20106 of the Michigan Compiled Laws, where the patient resides. A witness shall not sign the designation unless the patient appears to be of sound mind and under no duress, fraud, or undue influence.

(4) A designation may include a statement of the patient's desires on care, custody, and medical treatment. The patient may authorize the patient advocate to exercise 1 or more powers concerning the patient's care, custody, and medical treatment, that the patient could have exercised on his or her own behalf.

(5) A patient may designate in the designation a successor individual as a patient advocate who may exercise powers concerning care, custody, and medical treatment decisions for the patient if the first individual named as patient advocate does not accept, is incapacitated, resigns, or is removed.

(6) Before its implementation a copy of the designation shall be given to the proposed patient advocate and shall be given to a successor patient advocate prior to the successor acting as patient advocate. Before acting as a patient advocate, the proposed patient advocate shall sign an acceptance to the designation.

(7) The acceptance to a designation as a patient advocate shall contain the following:

"(a) This designation shall not become effective unless the patient is unable to participate in medical treatment decisions.

(b) A patient advocate shall not exercise powers concerning the patient's care, custody, and medical treatment that the patient, if the patient were able to participate in the decision, could not have exercised on his or her own behalf.

(c) This designation cannot be used to make a medical treatment decision to withhold or withdraw treatment from a patient who is pregnant that would result in the pregnant patient's death.

(d) A patient advocate may make a decision to withhold or withdraw treatment which would allow a patient to die only if the patient has expressed in a clear and convincing manner that the patient advocate is authorized to make such a decision, and that the patient acknowledges that such a decision could or would allow the patient's death.

(e) A patient advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a patient advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.

(f) A patient advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the patient and shall act consistent with the patient's best interests. The known desires of the patient expressed or evidenced while the patient is able to participate in medical treatment decisions are presumed to be in the patient's best interests.

(g) A patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.

(h) A patient advocate may revoke his or her acceptance to the designation at any time and in any manner sufficient to communicate an intent to revoke.

(i) A patient admitted to a health facility or agency has the rights enumerated in section 20201 of the public health code, Act No. 368 of the Public Acts of 1978, being section 333.20201 of the Michigan Compiled Laws."

(8) The authority under a designation executed under this section shall be exercisable by a patient advocate only when the patient is unable to participate in medical treatment decisions. The patient's attending physician and another physician or licensed psychologist shall determine upon examination of the patient when the patient is unable to participate in medical treatment decisions, shall put the determination in writing, shall make the determination part of the patient's medical record, and shall review the determination not less than annually. If the patient's religious beliefs prohibit an examination and this is stated in the designation, the patient shall indicate in the designation how it shall be determined when the patient advocate shall exercise powers concerning decisions on behalf of the patient. If a dispute arises as to whether the patient is unable to participate in medical treatment decisions, a petition may be filed with the probate court in the county in which the patient resides or is found requesting the court's determination as to whether the patient is unable to participate in medical treatment decisions. If a petition is filed under this subsection, the court shall appoint a guardian ad litem to represent the patient for the purposes of this subsection. The court shall conduct a hearing on a petition under this subsection as soon as possible and within 7 days of the court's receipt of the petition. As soon as possible and within 7 days after the hearing, the court shall determine whether or not the patient is able to participate in medical treatment decisions. If the court determines that the patient is unable to participate in

medical treatment decisions, the patient advocate's authority, rights, and responsibilities shall become effective. If the court determines that the patient is able to participate in medical treatment decisions, the patient advocate's authority, rights, and responsibilities shall not become effective.

(9) An individual designated as a patient advocate under this section shall have the following authority, rights, responsibilities, and limitations:

(a) A patient advocate shall act in accordance with the standards of care applicable to fiduciaries in exercising his or her powers.

(b) A patient advocate shall take reasonable steps to follow the desires, instructions, or guidelines given by the patient while the patient was able to participate in care, custody, or medical treatment decisions, whether given orally or as written in the designation.

(c) A patient advocate shall not exercise powers concerning the patient's care, custody, and medical treatment that the patient, if the patient were able to participate in the decision, could not have exercised on his or her own behalf.

(d) This designation cannot be used to make a medical treatment decision to withhold or withdraw treatment from a patient who is pregnant that would result in the pregnant patient's death.

(e) A patient advocate may make a decision to withhold or withdraw treatment which would allow a patient to die only if the patient has expressed in a clear and convincing manner that the patient advocate is authorized to make such a decision, and that the patient acknowledges that such a decision could or would allow the patient's death.

(f) A patient advocate under this section shall not delegate his or her powers to another individual without prior authorization by the patient.

(10) A designation executed under this section is suspended when the patient regains the ability to participate in medical treatment decisions. The suspension is effective as long as the patient is able to participate in medical treatment decisions. If the patient subsequently is determined under subsection (8) to be unable to participate in medical treatment decisions, the patient advocate's authority, rights, responsibilities, and limitations shall again become effective.

(11) A designation executed under this section is revoked by any of the following:

(a) The death of the patient.

(b) An order of dissolution by the probate court under subsection (16).

(c) Resignation of the patient advocate or removal of the patient advocate by the probate court, unless a successor patient advocate has been designated.

(d) Revocation of the designation by the patient. Even if the patient is unable to participate in medical treatment decisions, a patient may revoke a designation at any time and in any manner by which he or she is able to communicate an intent to revoke the designation. If there is a dispute as to the intent of the patient to revoke the designation, the probate court may make a determination on the intent of the patient to revoke the designation. If the revocation is not in writing, a person who witnesses a revocation of a designation shall describe in writing the circumstances of the revocation, shall sign the writing, and shall notify, if possible, the patient advocate of the revocation. If the patient's physician or health facility has notice of the patient's

revocation of a designation, the physician or health facility shall note the revocation in the patient's medical records and bedside chart, and shall notify the patient advocate.

(e) A subsequent designation that revokes the prior designation either expressly or by inconsistency.

(f) The occurrence of a provision for revocation contained in the designation.

(g) If a designation is executed during a patient's marriage naming the patient's spouse as the patient advocate, the designation shall be suspended during the pendency of an action for separate maintenance, annulment, or divorce and shall be revoked upon the entry of a judgment of separate maintenance, annulment, or divorce, unless the patient has named a successor individual to serve as a patient advocate. If a successor patient advocate is named, that individual shall act as the patient advocate.

(12) The revocation of a designation of a patient advocate under subsection (11) does not revoke or terminate the agency as to the patient advocate or other person who acts in good faith under the designation and without actual knowledge of the revocation. An action taken without knowledge of the revocation, unless the action is otherwise invalid or unenforceable, binds the patient and his or her heirs, devisees, and personal representatives. An affidavit executed by the patient advocate stating that he or she did not have at the time of doing an act pursuant to the designation actual knowledge of the revocation of the designation is, in the absence of fraud, conclusive proof that the patient advocate did not have actual knowledge of the revocation at that time of the revocation.

(13) A current desire by a patient, irrespective of a previous expressed or evidenced desire, to have provided, and not withheld or withdrawn, a specific life extending care, custody, or medical treatment shall be binding on the patient advocate, if known by the patient advocate, regardless of the then ability or inability of the patient to participate in care, custody, or medical treatment decisions or the competency of the patient.

(14) A person providing, performing, withholding, or withdrawing care, custody, or medical treatment as a result of the decision of an individual who is reasonably believed to be a patient advocate and who is reasonably believed to be acting within the authority granted by the designation, is liable in the same manner and to the same extent as if the patient had made the decision on his or her own behalf.

(15) A person providing care, custody, or medical treatment to a patient is bound by sound medical practice and by the instructions of a patient advocate if the patient advocate complies with this section, and is not bound by the instructions of a patient advocate if the patient advocate does not comply with this section.

(16) If a dispute arises as to whether a patient advocate is acting consistent with the patient's best interests, or is otherwise not complying with this section, a petition may be filed with the probate court in the county in which the patient resides or is found requesting the court's determination as to the continuation of the designation or the removal of the patient advocate.

(17) A patient advocate cannot make a medical treatment decision under the authority of or under the process created by this section to withhold or withdraw treatment from a pregnant patient that would result in the pregnant patient's death.

(18) A health care provider shall not require a designation to be executed as a condition of providing, withholding, or withdrawing care, custody, or medical treatment.

(19) A life or health insurer shall not do any of the following because of the execution or implementation of a designation or because of the failure or refusal to execute or implement a designation:

(a) Refuse to provide or continue coverage to the patient.

(b) Limit the amount of coverage available to a patient.

(c) Charge a patient a different rate.

(d) Consider the terms of an existing policy of life or health insurance to have been breached or modified.

(e) Invoke a suicide or intentional death exemption or exclusion in a policy covering the patient.

(20) A designation executed under this section shall not be construed to condone, allow, permit, authorize, or approve suicide or homicide.

(21) Except as provided in subsections (18) and (19), this section shall only apply to or affect a person who has executed a designation. This section shall only apply to or affect a person acting for or on behalf of another person who has executed a designation.

(22) Nothing in this section shall be considered to authorize or compel care, custody, or medical treatment decisions for a patient who objects on religious grounds.

(23) A designation executed before the effective date of this section with the intent of accomplishing a similar purpose as this section is valid but shall be subject to subsection (1) and subsections (4) through (23), shall be in writing, signed, witnessed or notarized, dated, executed voluntarily, and before its implementation shall be made part of the patient's medical record.